

# Advance Directives

## Why are advance directives important?

Complex choices about end-of-life care are difficult even when people are well. If a person is seriously ill, these decisions can seem overwhelming. But patients should keep in mind that avoiding these decisions when they are well may place a heavier burden on them and their loved ones later on. Communicating wishes about end-of-life care will ensure that people can face the end of their lives with dignity and with the same values by which they have lived.

## What rights do patients have regarding their medical treatment?

Patients are entitled to complete information about their illness and how it may affect their lives, and they have the right to share or withhold that information from others. Patients have the right to make decisions about their own care. These decisions may change over time. In the face of worsening disease, some patients may want to try every available drug or treatment in the hope that something will be effective. Other patients may choose to forgo aggressive medical treatment. Many patients turn to family members, friends, or caregivers for advice. But it is the patient's decision how much or how little treatment to have. Sometimes a patient is unable to make this decision, due to severe illness or a change in mental condition.

## What is end-of-life care? What are advance directives?

End-of-life care is a general term that refers to the medical and psychosocial care given in the advanced or terminal stages of illness. Advance directives are the legal documents, such as the living will, durable power of attorney and health care proxy, which allow people to convey their decisions about end-of-life care ahead of time. Advance directives provide a way for patients to communicate their wishes to family, friends, and health care professionals and to avoid confusion later on, should they become unable to do so.

Ideally, the process of discussing and writing advance directives should be ongoing, rather than a single event. Advance directives can be modified as a patient's situation changes. Even after advance directives have been signed, patients can change their minds at any time.

## Why is it important to write a will?

A will is important so that patients can give instructions about distribution of their money and property when they die. Patients can name a trusted family member, friend, or professional to handle their personal affairs (also known as an Executor). It is advisable to seek the expert advice of a lawyer in drawing up a will so that the decisions made about taxes, beneficiaries, and asset distribution will be legally binding. This process can relieve a patient's family and friends of an enormous burden in case of disputes or questions about allocation of the patient's assets.

## What is a living will?

A living will is a set of instructions documenting a person's wishes about medical care intended to sustain life. It is used if a patient becomes terminally ill, incapacitated, or unable to communicate or make decisions. Everyone has the right to accept or refuse medical care. A living will protects the patient's rights and removes the burden for making decisions from family, friends, and physicians. There are many types of life-sustaining care that should be taken into consideration when drafting a living will. These include:

- The use of life-sustaining equipment (dialysis machines, ventilators, and respirators);

- "Do not resuscitate" orders; that is, instructions not to use CPR if breathing or heartbeat stops;
- Artificial hydration and nutrition (tube feeding);
- withholding of food and fluids;
- Palliative/comfort care; and
- Organ and tissue donation.

It is also important to understand that a decision not to receive "aggressive medical treatment" is not the same as withholding all medical care. A patient can still receive antibiotics, nutrition, pain medication, radiation therapy, and other interventions when the goal of treatment becomes comfort rather than cure. This is called palliative care, and its primary focus is helping the patient remain as comfortable as possible. Patients can change their minds and ask to resume more aggressive treatment. Any changes in the type of treatment a patient wants to receive should be reflected in the patient's living will.

Once a living will has been drawn up, patients should talk about their decisions with the people who matter most to them, especially family and health care providers, explaining the values underlying their decisions. Most states require that the document be witnessed. Then it is advisable to make copies of the document, place the original in a safe, accessible place, and give copies to the patient's doctor, hospital, and next of kin. Patients may also want to consider keeping a card in their wallet declaring that they have a living will and where it can be found.

### **What is a health care proxy and durable power of attorney for health care?**

A health care proxy is an agent (a person) appointed to make a patient's medical decisions if the patient is unable to do so. Generally, people assign someone they know well and trust to represent their preferences when they can no longer do so. Patients should be sure to ask this person for agreement to act as their agent. An agent may have to exercise judgment in the event of a medical decision for which the patient's wishes are not known.

The durable power of attorney for health care is the legal document that names a patient's health care proxy. Once written, it should be signed, dated, witnessed, notarized, copied, distributed, and incorporated into the patient's medical record.

Patients may also want to appoint someone to manage their financial affairs if they cannot. This is called a durable power of attorney for finances, and is a separate legal document from the durable power of attorney for health care. Patients may choose the same person or someone different from their health care proxy to act as their agent in financial matters.

Appropriate forms can also be obtained from health care providers, legal offices, Offices on Aging, and state health departments.

***Note: This information is not intended to serve as legal advice. Although a lawyer is not needed to complete advance directives, it is important to be aware that each state has its own laws for creating advance directives. Because these laws can vary in important details, special care should be taken to adhere to the laws of the state a patient lives in or is treated in. It is possible that a living will or durable power of attorney signed in one state may not be recognized in another.***

*"This document was adapted with permission by Federal Occupational Health from CancerCare (www.cancercare.org), a national nonprofit organization that provides free professional counseling, education, financial assistance and practical help to people with cancer and their loved ones."*